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Recommended Citation

Elizabeth F. Emens, Kaaryn S. Gustafson & Jasmine E. Harris, *The Disability Cost Narrative: A Roundtable Discussion*, 170 U. PENN. L. REV. 1951 (2022).

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TRANSCRIPT

THE DISABILITY COST NARRATIVE: A ROUNDTABLE DISCUSSION

The dominance of “cost narratives” in disability law and discourse warranted the inclusion of a scholarly roundtable discussion devoted to the topic. The transcription below captures this discussion among three disability legal scholars: Professors Elizabeth F. Emens,[†] Kaaryn S. Gustafson,^{††} and Jasmine E. Harris.^{†††}

Jasmine Harris:

Good afternoon, everyone. My name is Jasmine Harris, and I’m a professor of law here at Penn Carey Law School. Just to identify myself, I am a Latina with brown hair, brown eyes, wearing a navy-blue blazer, blue and white striped shirt with a beaded necklace, gold earrings and glasses. My pronouns are she/her/hers, and I have the pleasure of serving as both moderator and participant here. I am delighted to be joined by Professor Elizabeth Emens and Professor Kaaryn Gustafson.

This round table focuses on what we are calling “the cost narrative,” that is the notion that disability accommodations, and disability rights are costly. This is a narrative that goes to the heart of debates about disability rights. The question of costs weighs heavily on, and shapes the very operation of, disability frames that you have heard about this morning and will continue to hear about throughout the course of this symposium.

One inspiration for this symposium came from a story that ran in the *New York Times* that many of you have probably seen and read. It ran on July 21st, 2021, which just so happened to be five days before the 31st anniversary of the Americans with Disabilities Act (ADA). The article ran with the headline,

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The Man Who Filed More Than 180 Disability Lawsuits, and posed the question, is it profiteering or justice?¹

Neither this story nor its type is new. Media outlets continue to depict people with disabilities in ADA Title III accessibility litigation as “crybabies”² or “serial plaintiffs,”³ looking for handouts for their payday and manipulated by “greedy abusive lawyers” who construct these “drive by” lawsuits. These types of cases are also called “Google lawsuits,”⁴ because the belief is that lawyers use the images on Google Earth to zoom in on individual streets, down to the individual storefronts to see whether there are accessibility violations such as missing curb cuts or ramps. If so, the narrative is that these lawyers then solicit and recruit disabled plaintiffs to carry out their cases.⁵

It’s worth unpacking this for a moment to start off on equal footing, because it’s such a pervasive narrative that shapes these disability frames and shapes the political discourse. So, let’s start with congressional intent to demystify some of these.

First, Congress intentionally designed the Americans with Disabilities Act (ADA) to deputize individual plaintiffs as private attorneys general, to be a critical part of the enforcement efforts under Title III of the ADA to address discrimination in public accommodations.⁶

While some may raise their eyebrows at the thought of private attorneys general as civil rights tool, many should also recognize that this is the civil rights enforcement structure that came from Title II of the Civil Rights Act of 1964, addressing discrimination by owners or operators of places of public accommodations in the context of race, color, religion, or national origin.⁷

Title II of the Civil Rights Act in 1964 was a model for Title III of the ADA in the late 1980s leading up to its promulgation in 1990. Congress understood the ADA principally as an extension of existing civil rights laws to people with disabilities who were not an enumerated class in the original Civil Rights Act.

¹ Lauren Markham, *The Man Who Filed More Than 180 Disability Lawsuits*, N.Y. TIMES MAGAZINE (July 21, 2021), <https://www.nytimes.com/2021/07/21/magazine/americans-with-disabilities-act.html>.

² *Crybabies*, THIS AMERICAN LIFE (Sept. 24, 2010).

³ Markham, *supra* note 1.

⁴ Brian Carnie & Michael Lowe, *ADA Access: “Drive By” or “Google” Lawsuits and the Americans with Disabilities Act?* LA. L. BLOG (Feb. 3, 2017), <https://www.louisianalawblog.com/labor-and-employment-law/ada-access-drive-google-lawsuits-americans-disabilities-act/>.

⁵ See SEYFARTH SHAW BLOG, (Dec. 9, 2016), <https://www.adatitleiii.com/2016/12/controversial-60-minutes-segment-on-drive-by-ada-lawsuits-highlights-negative-aspect-of-the-law/> (discussing Anderson Cooper’s controversial 60 Minutes story on “drive by” ADA litigation).

⁶ Americans with Disability Act of 1990, 42 U.S.C. §§ 12181-89.

⁷ Civil Rights Act of 1964, 42 U.S.C. §§ 2000a-2000a-6.

In crafting the private right of action under Title III in the context of disability, Congress, in part, understood the realities of enforcement, for example, that agencies alone could not possibly address the sheer numbers of architectural and programmatic barriers in a world that was built for able bodies and neurotypical minds. In this sense, private enforcement was central to congressional intent. This legal design then allowed for private individuals to take on enforcement responsibilities one by one, as they experienced or noticed them.

Second, Congress explicitly negotiated limits on private rights of action for individual plaintiffs under Title III: the absence of monetary damages (with some limited exceptions). In other words, Congress said, “you, private individuals, will go out and carry out our intent,” which is to make this a more accessible, barrier-free society but you may only request injunctive relief and reasonable attorneys’ fees.

And so, the windfall phenomenon propagated by many operators of public accommodations and the press is not a federal phenomenon. Some states like California have passed legislation that allow plaintiffs to recover a capped amount of money of damages per violation. But to be clear, this is not a function of the Americans with Disabilities Act, and attorney’s fees would cover the time private lawyers spend litigating this case as fee shifting statutes allow lawyers to take these cases and represent private attorneys general.

Third, people with disabilities in these cases are depicted in one of two ways, as either “pawns” subject to the manipulation by greedy lawyers, or as greedy individuals simply seeking to get over on the system. Nothing is said about the legitimacy of their accessibility claims, particularly thirty-one years after the Americans with Disabilities Act.

The principal complaint advanced by business owners and operators under Title III is that they are expected to comply with onerous and costly accessibility standards that they did not receive notice of in advance. Many defendants will admit that their restroom is not accessible but fault the plaintiff and the ADA for failing to notify them and offer sufficient time to fix it. One demonstrative used by media reports is the effect of ADA compliance on small business owners, particularly in immigrant communities.

The emphasis on cost exemplified by stories of immigrant-owned small businesses going under because of Title III lawsuits utilizes a notice and fairness frame which, in turn, has fueled the introduction of a number of federal bills seeking to amend the Americans with Disabilities Act, including in 2017, H.R. 620, which was aptly titled the ADA Education and Reform Act.⁸ Its principle amendment was to add additional administrative procedures to give the owners and operators additional notice of a potential

⁸ ADA Education and Reform Act of 2017, H.R. 620, 115th Cong. (2017).

violation and an opportunity to cure. That would add intervals of 60 days, and a cure could be something as simple as a specific plan for improvements, not the improvements themselves. Although the bills moved through Congress, they did not make it all the way to law.

So, what does this say to us? It signals the pervasiveness and persuasiveness of these narratives in public discourse.

So today, during this round table, I want to present two meta questions, one descriptive and the other normative. The first is how do we think about costs in the context of disability rights? That's the descriptive question. And the second question is normative, and I really want us to push on this. How should we think about costs?

According to the news article that I started with, the author writes, "The trouble with accessibility litigation is that the discussion always seems to boil down to money."⁹ So why is costs such a pervasive narrative? A few thoughts. First, the ADA itself was the product of bipartisan efforts that brought people like Senators Bob Dole (Kansas-Republican) and Tom Harkin (Iowa-Democrat) to the same table.

By 1990, attacks on the welfare state resulted in fiscal conservatism. The ADA was marketed as an anti-welfare bill that would move people with disabilities from welfare to work and from state dependence to fiscal independence and responsibility. The literature on law and political economy helps us to understand the connection between capitalism and production, and the stigma associated with disability precisely because disability was understood as unemployable, unproductive, and dependent on the state, as the first panel today discussed. The standard law and econ cost-benefits analysis serves as our main evaluative measure with limited, and highly normative inputs.

Second, why do we have this cost narrative? We have the cost narrative itself because the law allows for cost considerations as affirmative defenses, like undue burden and undue hardship. Because of this, discussions about disability rights often come with cost caveats. Even scholars themselves reinforce the cost narrative. For example, some of the most cited empirical research is on costs and says that most reasonable accommodations cost nothing or are de minimis.¹⁰ The Job Accommodation Network, for example,

⁹ Markham, *supra* note 1.

¹⁰ See, generally, Peter D. Blanck, *The Economics of the Employment Provisions of The Americans with Disabilities Act: Part I: Workplace Accommodations*, 46 DEPAUL L. REV. 877 (1997); *The Economics of the ADA*, in P. BLANCK, EMPLOYMENT, DISABILITY, AND THE AMERICANS WITH DISABILITIES ACT: ISSUES IN LAW, PUBLIC POLICY, & RESEARCH, 201-27 (2000).

has surveyed a cross section of employers since 2004. Fifty-six percent of the employers surveyed reported zero to de minimis (approximately \$500).¹¹

What is this research telling us? It's trying to convince us that the cost of providing disability accommodations, the cost of equity and inclusion is de minimis. I realized that when I teach disability law, I assign these materials on cost and may, in some ways, reinforce the legitimacy of this cost narrative, that is, reasonable accommodations are not costly and, therefore, ought to be enforced.

We need to think more broadly about what constitutes cost in the context of disability. The cost narrative most often focuses on monetary costs to private businesses who need to comply with disability law, but the cost conversation needs to be much broader and much more nuanced where the stakes and the stakeholders are clearer. Is equality costly? As compared to what? Yes, it costs more money to end child labor. It costs more money to pay women and people of color the same as white men for their labor. But as a society, we have come together, voted, and decided that inequitable pay based on sex or race is not acceptable. The financial costs are outweighed by the cost to human dignity and to our democracy.

This round table will discuss other conceptions of costs and how and why we might change the cost narrative to better reflect these considerations. Law is highly normative. As Nate Holdren said earlier today, the decision to tie disability to need supports has prevented wealth accumulation among people with disabilities. And in my work, the law's preference for risk aversion, with respect to people with disabilities, has resulted in less experiences with decision-making for people with intellectual and developmental disabilities, for example, and high rates of conservatorship and guardianship, denying people with disabilities the right to make decisions about their lives.¹² These are costs that are not captured by our classic law and econ measures.

So today, I would like us to talk more about the normative, that is to say, how do we think about costs and what factors should we consider in thinking through cost? And then we can ask the follow-up question, which is, how do we then move to that system prescriptively? I'll end here, and I will add more in the Q&A later. But what I'd like to do is turn this over to Professor Emens to give some introductory comments and remarks. Thank you very much.

¹¹ *Accommodation and Compliance: Low Cost, High Impact*, JOB ACCOMMODATION NETWORK (Oct. 21, 2020), <https://askjan.org/topics/costs.cfm>.

¹² See, generally, Jasmine E. Harris, *Sexual Consent and Disability*, 93 N.Y.U. L. REV. 480 (2018); Jasmine E. Harris, *The Role of Support in Sexual Decision-Making for People with Intellectual and Developmental Disabilities*, 77 OHIO ST. L.J. 83 (2016).

Elizabeth Emens:

Thank you so much. What a delight and an honor to be in the wonderful company of these distinguished co-panelists, Professor Gustafson and Harris, and this whole amazing symposium. For my part. I'm Liz Emens, a white woman with glasses, wearing a black sweater, and a black blouse, and a silver circular necklace (that I wear so often, it's how people recognize me with a mask on, on the street), against a background of a green and white wood-framed panel, abstract, that maybe looks like grass, and a plant. My pronouns are she/her. Echoing a lovely moment in Karen Tani's welcome this morning, I'm smiling widely to see you all here and to know you all are here, those I cannot see as well.

If there's anything I can do to make my presentation more accessible, or if I'm speaking too quickly, I really want to know. I have trouble reading the chat and focusing while I'm speaking, but I believe that Professor Harris will be monitoring it and will let me know if something comes up, somehow. I want to pause also for just a moment to express my gratitude to the *Law Review* and the other organizers, and everyone behind the scenes whom we don't see, or at least I don't know about, who's contributed to making this event possible.

As part of that, I also want to briefly acknowledge the land on which our host institution resides, which I understand to be the traditional territory of the Lenni Lenape people, on whose traditional territory my home institution also rests. I want to pay my respects to the elders of Lenape, both past and present. If we had more time, I'd offer a longer version of this land acknowledgement, but please let's just take a moment to consider the many legacies of violence, displacement, migration, and settlement that bring us here together today, and to honor all Indigenous First Nation peoples, particularly those on whose land our institutions reside.

Turning to our theme of the cost frame, I plan to talk about three of the ways the cost frame has struck me as especially salient in the articulation of the legal doctrine surrounding reasonable accommodation under ADA Title I,¹³ and particularly some thinking I've especially done around the third-party benefits of reasonable accommodation in the integration presumption set forth in the IDEA¹⁴ and elsewhere and in institutional diversity initiatives. Then I'll talk a little about my current grappling with the cost frame and a new project I'm beginning and invite your ideas and input.

I saw the dominance of the cost frame for talking about accommodations and disability, particularly when I began presenting a much earlier project, the first or second thing I wrote as a baby academic, on the third-party

¹³ Americans with Disability Act of 1990, 42 U.S.C. §§ 12181-89.

¹⁴ Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-82.

benefits of disability accommodations.¹⁵ In that project, the core descriptive observation was that courts had articulated reasonable accommodation and undue hardship in terms of a loose balancing of costs and benefits, and, as Professor Harris was just talking about, had taken into account benefits to the person with a disability, costs to the employer, and cost to third parties, like coworkers and customers. But courts and commentators were failing to notice or take into account third-party benefits, that is, the benefits the accommodation might yield to coworkers or customers, whether disabled or non-disabled under the ADA's definition, or in between.

The first time I presented this project was an early ideas workshop for juniors at my own institution. We were a small and generally supportive group. I was also new and somewhat nervous. The first question I got in this workshop was from a colleague who had, I think, read my five-page project description, which was all about how people talk only about costs when they talk about disability and neglect to talk about the benefits. I was specifically focusing on a piece of the legal doctrine that was just missing. If you have a box with this kind of benefit and this kind of cost and then you have this kind of cost, then you would also have this kind of benefit. We're just missing a piece of the puzzle; it seemed fairly obvious once one was looking at it.

Anyway, this guy raised his hand. The first thing he said, really smart guy, his question essentially was, "But don't we have to talk about the costs?" It was like there was no other entry point for him in talking about disability other than the costs. I was struck in this, and related exchanges, by how trenchant the cost frame was, such that even those trained to focus their attention on nuanced arguments were stuck in the frame of costs and couldn't seem to get out.

We can also see the cost frame in a striking way in the law and policies surrounding the integration mandate, for instance, under the Individuals with Disabilities in Education Act, the IDEA.¹⁶ The orientation in privileging contact in legal representations of integration is almost always cast as the value to disabled people of contact with non-disabled people. The least restrictive environment requirement under the IDEA, for instance, requires states to ensure that, "To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled."¹⁷

A requirement like this, that disabled students have a certain amount of exposure to non-disabled students, projects a message of one-way benefits, flowing exclusively from non-disabled to disabled. Of course, this also

¹⁵ See, e.g., Elizabeth F. Emens, *Integrating Accommodation*, 156 U. PA. L. REV. 839 (2008).

¹⁶ Individuals with Disabilities Education Act, 20 U.S.C. §§ 1412(a)(5)(A).

¹⁷ *Id.*

assumed a clear divide. We see an assumption here, in the legal imagination, that non-disabled students provide benefits, with the implied contrast to the presentation of disabled students as imposing costs.

There is some interesting new work by Yaron Covo on reverse mainstreaming, with empirical findings about the situations earlier discussed by Ruth Colker, wherein non-disabled students are introduced into settings predominantly for disabled students.¹⁸ As Covo demonstrates in really interesting ways, arguably the cost frame still predominates, even though this situation of reverse integration might in principle seem to suggest the possibility of a shift in frame of who's providing the benefits. If Yaron is here, perhaps he will say more about the connections he's finding.

The cost frame can be seen in so many places. I'll just mention one other area before turning to my own grappling with the cost frame in a current project. I've also thought about the cost frame in relation to disability when thinking and writing about diversity initiatives and the ways that they still so rarely include disability as an affirmative source of diversity to be sought out, recruited, or appreciated. Various folks have also written about this issue of lack of inclusion in diversity initiatives, including Lauren Shallish and Lennard Davis, more extensively than I have, for certain.¹⁹ It was just brought to the front of my mind, though, this week, as an LLM student from abroad marveled to me at the way disability is left out of diversity talk.

This seems to me directly related to the cost frame in two senses. First, the exclusion of disability from diversity initiatives may be fueled by fears of the actual costs of disability accommodation. This goes back to what Professor Harris was talking about too, about who bears the costs and the whole structure of, say, the ADA, fears that so often exaggerate the actual cost of accommodation, as the work of Peter Blanck and others have argued.²⁰ Second, and more broadly, the diversity frame for anti-discrimination efforts is affirmative in general, focused on the positive contributions that stem from identity, in ways that scholars who favor a thin conception of identity critique, of course.

But disability is so often framed by costs, by lack, in the public imagination that for many people, it seems, I think, often hard for them, for

¹⁸ Yaron Covo, *Reversing Reverse Mainstreaming*, 75 STAN. L. REV. (forthcoming 2023) [on file with law review].

¹⁹ See generally Lauren Emily Shallish, *Is Disability a Diversity Issue?: Diversity Workers and the Construction of Disability in Higher Education* (2016) (PhD dissertation, Syracuse University), <https://surface.syr.edu/etd/527>; Lauren Emily Shallish, "Just How Much Diversity Will the Law Permit?": *The Americans with Disabilities Act, Diversity and Disability in Higher Education*, 35 DISABILITY STUD. QUARTERLY 3 (2015), <https://dsq-sds.org/article/view/4942/4059>; LENNARD J. DAVIS, *THE END OF NORMAL: THE END OF IDENTITY IN A BIOCULTURAL ERA* 5-14 (2013).

²⁰ See, e.g., Blanck, *supra* note 10.

the institutional designers, to imagine disability as one of those affirmative identities, contributing something positive rather than framed entirely by this cost narrative that no one can seem to get away from. I don't mean no one, but I mean no one in the mainstream institutional designer world, although there are certainly exceptions now.

Now I'm beginning a new project, which I'll speak about just briefly, but which I welcome your input on, and which I'm really struggling with how to pursue without having it swallowed up or derailed by the cost frame, given the dominance of the cost frame. This new project is focused on how the soft costs, or what I might call "admin" costs of providing accommodation, are distributed within institutions.²¹ Among those required to provide the accommodations, in other words, the second-party costs, the cost to the employer institution, who has to do them, who does the work, the labor of providing accommodations?

The idea that sparked this project for me stems from my observation, anecdotal at this point—I'm beginning to do research on this—that the labor costs of providing accommodation are often shunted off onto frontline workers who receive little guidance, support, recognition, or compensation for doing this additional work. These costs are often invisible and create a drag on the integration of those disabled people who require accommodations, because those tasked with implementing them don't get the support they need to do so, with notable exceptions, which I'm also interested in studying.

My project is to try to understand these labor costs, this dynamic of distribution within institutions. One context that got me thinking about this was Haben Girma's TED Talk, which many of you have probably seen, along with 300,000 or so other people around the world, where she talks about the cafeteria workers who, when she was in college, wouldn't reliably provide her with menus by email, as a deaf-blind student, until she threatened to sue them.²² They said that they would email her the menus before each meal, but they constantly forgot. When she complained, the cafeteria workers basically said they were busy, they were doing her a favor and she should be grateful that they tried at all. Eventually, she threatens to sue. She says she doesn't know how she would've sued at that point, she didn't know that, she hadn't gone to law school yet, but she says this changed the story. It's the aha moment for her about the power of legal advocacy.²³

²¹ See, generally, Elizabeth F. Emens, *Disability Admin: The Invisible Costs of Being Disabled*, 105 MINN. L. REV. 2329 (2021); ELIZABETH F. EMENS, LIFE ADMIN: HOW I LEARNED TO DO LESS, DO BETTER, AND LIVE MORE (2019).

²² TEDx Talks, *Why I Work to Remove Access Barriers for Students with Disabilities*, YOUTUBE (Feb. 28, 2014), <https://www.youtube.com/watch?v=Mvoj-ku8zko>.

²³ *Id.*

But the cafeteria workers in the story are portrayed as unsympathetic figures who don't get disability or the need for accommodation, as evidenced by their complaining about having to send one email before the meals. Well, after I'd spent the last several years conducting interviews and otherwise researching small administrative burdens that add up for people, including my most recent article that's about disability admin and the admin costs of medical admin, benefits admin and discrimination admin for disabled people,²⁴ it got hard for me to see that the idea of having to send one email before every meal to one or maybe more students of a menu for cafeteria workers who aren't office workers, presumably, that that was nothing. It didn't seem like nothing.

I found myself thinking, not that the email shouldn't be sent—of course Haben Girma should have been getting the menus reliably, and she shouldn't have had to negotiate or hassle or threaten to sue to make that happen, she shouldn't have had to do that kind of discrimination admin—but I now found myself asking other questions, like where is the college's Disability Services Office in all of this? Why don't the cafeteria workers get any support with this, either directly with accommodating Girma or at least with remembering to send the emails at each mealtime? If we know that small acts, like having to fill out a form to opt into a retirement plan can have big effects on enrollment rates, then why would we view this additional labor put on frontline cafeteria workers as meaningless?

My thinking about this also sparked from working at one point in an institution where there was actually an incredibly centralized authoritative system for delivering screen reader-accessible reading materials to students that meant that all reading materials that went to all students had to, from the front end, be accessible, rather than this being a response to requests from individual students, which made me realize how different institutions are in their institutional design of how that labor is set up and structured. I got interested in trying to find out how is this labor distributed within institutions and what are best case scenarios, and what's often done and who's bearing this.

I'm interested here in power and class and race and other intersectional dimensions of who may end up tasked with the hidden costs of providing accommodation. But I'm also haunted by the cost frame. My concern is that talking about the hidden costs of accommodation may just give those stuck in the cost frame just one more reason to think in terms of cost. Yet, I'm afraid if we don't talk about it it's this invisible drag on integration and it lets institutions off the hook who don't want to talk about it, because if it were acknowledged in some way, there might be some need to actually compensate

²⁴ Emens, *Disability Admin*, *supra* note 21.

and support these frontline workers who may be doing this work. I think that also sets people with disabilities up for microaggressions. When there's no systemic approach taken to how the disability accommodations are going to be provided, then every request is a demand that is met with, "I don't know what to do," by the person who's asked to do it, who may already be overworked in any number of ways.

I'm very interested—I'm setting up interviews right now, designing a protocol for this, and if people have ideas for who I might interview or how to frame this or how to get out of the cost narrative, I would be so grateful. Thank you.

Jasmine Harris:

Thank you, Professor Emens. Professor Gustafson, I'm going to turn this over to you for your introductory remarks.

Kaaryn Gustafson:

Thank you. My name is Kaaryn Gustafson. I am a professor at UCI School of Law, and I use she/her pronouns. I am a multiracial Black-identified woman with brown skin and big curly hair and glasses. I'm wearing a blue shell and a black sweater. What may not be obvious through Zoom is that I have a visible disability and move through the world using a wheelchair.

Before I begin, I have to thank Professors Karen Tani and Jasmine Harris for their work in organizing this amazing conference, and for editor, Matthew Seelig, and his co-editors at *UPenn Law Review*, for overseeing the many details that go into a virtual conference. Thank you.

Today, the title of my comments is *Tallying the Expendables Through a Disability Frame*. Liz Emens's notable article from 2012 discusses the importance of framing disability from the inside rather than the outside.²⁵ From the outside, disability is seen as a negative quality, a problem for society, a source of burden and a cost on society. Disability is an individual quality, rather than a social construct that applies to a marginalized subset of the population.

Cost-benefit analyses that tend to dominate discussions of disability do two things. One is the cost-benefit narrative tends to frame government or social costs, or even private costs, as cost to non-disabled hardworking taxpayers, which situates people with disabilities as a discrete group, non-contributors to a capitalist society that values only producers and consumers. It positions people with disabilities as takers, as dependent.

Second, the cost-benefit analysis tends to measure costs, at least in the United States, in dollars. What is ignored in measuring in dollars only? Lives.

²⁵ Elizabeth F. Emens, *Framing Disability*, 2012 ILL. L. REV. 1383, 1387-88.

The outside disability frame and the dominant cost-benefit frame render people in various problematic ways. People with disabilities are rendered as invisible, burdensome, and expendable. Now, the notion of expendability suggests that society would be better off without people with disabilities, despite the likelihood that most people will experience disability at some point in life.

Today, I'm going to talk about how we might bring the disability frame to cost-benefit analysis by tallying the expendables. This is a call to include body counts, specifically predictions or tallies of premature deaths, or in some contexts, excess deaths, with policy proposals as a way of measuring the human harms that come with policy decisions.

Sociologist Eric Klinenberg offers an example of ways that the outside disability frame and additional cost-benefit analysis apply in natural disasters.²⁶ He notes that public concern about natural disasters tend to focus on big, spectacular events, for example, earthquakes, wildfires, tornadoes, hurricanes, and floods. He notes that the natural disasters with the highest death tolls, which we rarely discuss, are heat waves.²⁷

Why does the American public and why do public officials not take into account the costs of heat waves? There are two reasons. First, we tend to measure the impact of natural disasters in property loss, measured in dollars. Second, the people who die in heat waves tend to be those at the outer margins of society—the elderly, the poor, the unhoused, and disabled—those with the least political influence and commonly viewed as burdens on society rather than full members of society.²⁸

Let me introduce two concepts. One is “the expendables.” The expendables are people who are neither economic producers nor consumers, and expendability is a system of state action and inaction that produces premature death of the expendables. Who are the expendables? They would be any subpopulation that experiences high rates of premature deaths. The groups tend to be those who aren't in the mainstream economy, but that's not always the case, as we're seeing with COVID. In the United States, they tend to be the non-working poor, people with addictions, people who are incarcerated, the non-working elderly, and the permanently disabled. Even the previous groups tend to have high rates of disability. If we look to New Orleans in the wake of Hurricane Katrina in 2005, we see that the people who were left behind were low-income people of color, the elderly, and those who

²⁶ See generally ERIC KLINENBERG, *HEAT WAVE: A SOCIAL AUTOPSY OF DISASTER IN CHICAGO* (2015).

²⁷ *Id.*

²⁸ *Id.*

were incarcerated. These are the expendables, and across all of those groups we see disability.

Now I'd like to talk about how we might bring the disability lens to a re-imagined cost narrative by tallying the expendables. This call to include body counts, as I mentioned before, to predict or tally premature deaths with all policy proposals is a way of measuring the most fundamental costs. Careful tallying of premature deaths would include tallies or projections that disaggregate data by axes of vulnerability, race, ethnicity, national origin, sexual orientation, gender identity, and most importantly for this discussion, disability. Tallying the expendables with a focused disability lens would involve a movement to demand that local, state, and federal officials find ways of assessing the impacts of their actions on the lives of people—especially those with disabilities—and not just measure their actions through dollars in their budgets.

Expendability and its focus on premature death is not only a theoretical concept, it is also a practical tool. It's a way of promoting disability awareness, mobilizing disability activists, and connecting disability rights with other social justice movements. Tallying the expendables—accounting for these unnecessary premature deaths—could occur as part of the routine budget process and might be a useful tool for many things.

For one, it would be useful in framing and illuminating social harms outside of traditional dollar-based cost-benefit analyses. It could also be useful for mobilizing social movement activists across lines of difference that tend to chill collaboration. For example, police shootings are currently framed as issues of racial injustice, but as Congress member Ayanna Pressley noted earlier in the program, these shootings are also disability injustices, as half of people who are the victims of fatal police shootings in this country have diagnosed disabilities.²⁹ My brilliant colleague, Jamelia Morgan, has produced work that highlights the weaknesses—in both existing policies and in legal doctrines—in protecting people with disabilities from police violence.³⁰ Where law is not working and where the people most vulnerable to state violence have little influence on democratic politics, movement work is needed.

Tallying the expendables can also be useful for making specific demands related to the fundamental wellbeing of those who are most vulnerable and for holding lawmakers and policymakers accountable for the decisions they make that imperil the lives of people with disabilities. With a movement

²⁹ See generally Vilissa Thompson, *Understanding the Policing of Black, Disabled Bodies*, *Center for American Progress* (Feb. 10, 2021), <https://www.americanprogress.org/article/understanding-policing-black-disabled-bodies>.

³⁰ Jamelia Morgan, *Policing Under Disability Law*, 73 *STAN. L. REV.* 1401 (2021).

aimed at tallying the expendables, activists can assemble and voters can examine the death counts of elected officials. Politicians who are running for office often tout their abilities to save tax dollars; however, we don't hear the estimates of how their decisions have affected lives, whether they have increased death rates in their districts or in the country.

Tallying the expendables would also be useful for shifting disability rights from a statutory entitlement to a more secure, fundamental right focused in equal protection. The Americans with Disabilities Act³¹ passed in 1990 individualized disability rights, as Professor Harris noted just a few minutes ago. It, in some ways, deflated the activist movement and shifted us to a new system, where individuals who have suffered disability discrimination or disability harm have the right to go to court and to sue. As Professor Harris has written, these *ex post* interventions aren't adequate remedies.³² We need *ex ante* interventions that will render transparent any disparate effects of policies and ultimately direct the focus of law and policy reforms to the predictable effects of those reforms for people with disabilities. Bringing a lens of expendability to our analysis is intended for movement lawyers and activists. This is another shift in the cost narrative. The cost narrative tends to be driven by litigators and judges but tallying the expendables would put the narrative in the hands of activists and movement lawyers.

I think I will leave it at that, given the time, but some of this tallying of the expendables is already being done in other contexts, I wanted to note that. Climate justice activists, for example, are doing this in calculating the effects of air pollution. They are predicting the premature deaths that occur as a result of air pollution in particular areas. There is one federal program, LIHEAP, the Low Income Home Energy Assistance Program, that uses predictions of deaths based on predictions of what the weather will be like in any given winter or summer. They use that to gauge geographic areas of vulnerability and excess deaths that will occur through carbon dioxide poisoning or exposure to extreme heat.³³ Now, it's not that predicted premature deaths aren't in the budget.³⁴ The way they are calculated in federal

³¹ Americans with Disabilities Act, 42 U.S.C. §§ 12101-213.

³² See, generally, Jasmine E. Harris, *Taking Disability Public*, 169 U. PA. L. REV. 1681 (2021) and *The Frailty of Disability Rights*, 169 U. PA. L. REV. ONLINE 29 (2020).

³³ See, e.g., January Contreras, *LIHEAP and Extreme Heat: How the Low-Income Home Energy Assistance Program is Assisting Families with Staying Safe, Healthy, and Prepared for Extreme Heat Events* (Apr. 22, 2022), <https://www.acf.hhs.gov/blog/2022/04/liheap-and-extreme-heat>

³⁴ Federal agencies use something called Value of Statistical Life (VSL) to analyze the premature mortality risks of policies. See, U.S. DEPT. OF TRANSP., GUIDANCE ON TREATMENT OF THE ECONOMIC VALUE OF STATISTICAL LIFE (VSL) IN U.S. DEPARTMENT OF TRANSPORTATION ANALYSES (Mar. 1, 2013), <https://www.transportation.gov/regulations/guidance-treatment-economic-value-statistical-life-us-department-transportation-analyses>.

policy right now is that these deaths are turned into dollar numbers and calculated into the cost-benefit analysis. I want to see the death counts, and I think they would be useful in shifting our frame from dollar costs to cost in lives. Thanks.

Jasmine Harris:

Thank you so much, Professor Gustafson, for those remarks. Just to manage everyone's expectations, what we're going to do from this point is I'm going to ask just a few opening questions and I'm seeing the Q&A start to grow, so hopefully you'll continue to add your questions there and we're going to leave ample time for that. Also, I invite my two co-panelists to just respond to each other as well and some of the things that you're thinking about. Please don't feel limited, that the whole format here is intended for us to be in conversation with one another.

With that, I do want to say that this is fascinating. I mean, we're all thinking that the cost narrative itself is problematic. Professor Gustafson says it is problematic, but as Professor Emens recognized, this is something that gets used and so let's figure out other measures that we can plug into the existing cost-benefit analysis, but broaden it, with death counts being one of them. Professor Emens says, "Well, you know what? We may not be able to escape the cost-benefit analysis. We either lean into it when we're trying to critique it, when we're offering alternative prescriptions to it." I think the key point here is how do we move past, and can we move past, the cost narrative? Professor Gustafson, you've started us thinking about this expendability, and I have a few questions on that for you.

Then the second part of it, I challenge us to say, well, what if we did away with the cost analysis altogether? This is our benefit of being in the ivory tower, we can think about this and say, what if we took out the cost caveats that are in the ADA? Professor Ruth Colker and I were exchanging some messages before this panel and she reminded me that the Rehabilitation Act³⁵ itself doesn't have, or at least initially did not have, the same cost affirmative defenses. Really, it came out of the regulations, which then get adopted into the ADA. Maybe we should collectively imagine a world where, in fact, the regulations never happened under 504³⁶—of course many people protested for those regulations—and how would we measure effectiveness? What would that mean? What would that mean for the provision of disability rights? It's the fear of the business and private sector to get rid of those caveats.

³⁵ Rehabilitation Act of 1973, 29 U.S.C. §§ 701-97.

³⁶ 29 C.F.R. § 32.13 (2019) ("A recipient shall make reasonable accommodation . . . unless the recipient can demonstrate that the accommodation would impose an undue hardship on the operation of its program or activity.").

Let me start with that question and direct it to both Professor Emens and Professor Gustafson. What if we did away with the cost narrative in the law itself? Would that get us anything? If so, what? And does that help advance your claims? In particular, the claim that you're working on right now, Professor Emens, which is to really rethink the design of institutional compliance to better understand the costs placed on, for example, essential workers tasked with doing the hard labor around accommodations. You're trying to get at those hidden costs.

Just a simple question to start, go ahead. [Laughter]

Elizabeth Emens:

I'm happy to jump in. The current project that I'm thinking about isn't really tied to the doctrinal architecture, in the sense that it isn't trying to tweak the calculus of costs and benefits so much anymore; it's really thinking about the internal institution dynamics. One of the things I've thought about is I may just talk about infrastructure, I mean, I could shift away from the frame entirely and not use the language of costs. It's also a way to make certain kinds of labor salient. I saw a comment, I think from Professor Belt in the Q&A, about how these discussions intersect with what it means to value or devalue women's labor, certain kinds of labor that is typically done by women.³⁷ And in one of the ways that some of the time that's done, is to talk about what it would be worth to do some of this kind of labor in a market setting, if it wasn't only women doing it. And again, that gets us within that loop of markets and costs and then we may want out of that loop.

But there is a way that it highlights the effort expended: if what we want to talk about is people who are vulnerable, who are then required to do extra things, to talk about that labor as a cost on them helps to make it salient to people who think in terms of that frame. Whether we could escape it . . . well, I'll say something that is, I suppose, oblique, but I think we've had a natural experiment recently that takes us out of the cost frame in some sense with regard to accommodations, because we've had a massive global experiment in telecommuting. That is a debated accommodation under the ADA as to whether or not this is a reasonable accommodation. We have a circuit split on whether telecommuting is a reasonable accommodation,³⁸ but somehow it . . . as I understood it, I didn't hear it articulated in terms of the cost frame, when suddenly it was the way to get everybody to be able to work rather than just

³⁷ Rabia Belt, ZOOM ("How do we reconcile the problems with the cost/benefit framework with the feminist challenge to how non-renumerative labor/care work is inadequately recognized and valued?").

³⁸ Arlene S. Kanter, *Remote Work and the Future of Disability Accommodations*, 107 CORNELL L. REV. (forthcoming), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3895798

be at home under pandemic conditions, when it wasn't in the context of disability.

Now, at least I didn't hear it so much articulated in terms of costs. It was an opportunity. Isn't it amazing that we can do all this and institutions, I think, poured a lot of money into creating this infrastructure for enabling people to telecommute. Professor Harris, you and I have both written about the rhetoric around accommodations and how, as you put it, in publicity, how things are publicized.³⁹ Who talks about them and in what ways and how that shapes what's understood about them. And I've thought about this in relation to telecommuting in particular and how telecommuting initiatives are designed. And if they're designed in a way that just one person gets to stay and work at home, and everyone else picks up slack, if there is slack to pick up, that has one kind of meaning. Whereas if the prompt of one person needing that accommodation prompts the institutional designer to say, "Huh, maybe this is an accommodation that a lot of people could use and maybe it would actually work out well in our workplace. And let's use this as a prompt for redesign," then that can look rather different.

And the same goes for how it's understood that this one person is prompting this—is it depends on whether there's an ability to publicize their reasons for it, within their control, as opposed to disability always being treated as a privacy issue, which is often prohibitive of people organizing around disability within institutions, with people being able to announce it in an affirmative way, why they're getting accommodations and so on. So, I think we've seen that kind of natural experiment in what happens when you don't have disability in the frame. But I don't see yet how to put that together with the ADA. It seems to me, we would still end up stuck in the cost frame because of how pervasive it is within the disability narrative.

Jasmine Harris:

Pervasive and persuasive. I think that's what Professor Gustafson was saying. And then coming up with this concept of expendability seems . . . Professor Gustafson, is that the way that you're leaning in and saying, "Look, it's not only pervasive, but it is persuasive. And that people will find this compelling. This is how we do business and therefore let's find a way to communicate with people in their language."

Kaaryn Gustafson:

Yeah, and perhaps COVID has shifted individuals' assessments of risk to life and people may be more sensitive to measures of life versus just dollar costs. And I think, as Professor Emens notes in the widespread investment

³⁹ See, e.g., Emens, *supra* note 25, at 1387-88; Harris, *supra* note 32.

in the creation of infrastructures to allow telecommuting, we saw a realization that those were reasonable costs for people without disabilities. That they were reasonable costs to employers, and that there are costs to employers for having sick employees, for having employees who die. But something else I'd like to go back to in Professor Emens' comments, are the benefits. We don't talk about the benefits.

And when we're talking about labor costs to individuals associated with providing disability accommodations, if those individuals are adequately paid, we are also creating benefits to those individuals. We tend not to see the labor involved with disability. There are individual administrative costs of having a disability, but there's also labor produced through disability. It's not necessarily a loss for society, it's generative. And other countries with stronger healthcare systems or social welfare systems understand that, but in a society with such a thin safety net, we tend to always view caring costs as burdens, not as benefits to society. So, I may have veered off the question, but that's all I have.

Elizabeth Emens:

Can I come in just back on this?

Jasmine Harris:

Absolutely.

Elizabeth Emens:

This is so interesting and connects with something that I've been thinking about, which is what it takes to reimagine the labor of providing accommodations within an institutional context as valuable care work and as having relational meaning. I had a student last semester who talked about how within the context of an activist community that he's involved in, other people in that community have conveyed that they really appreciate . . . he finds it hard to ask for things, and that they've really conveyed to him fully and robustly that they really appreciate when he conveys his needs, because they actually really like meeting his needs as part of the relations of care within this community. And it has a completely different sense and valence than the cost frame. And yet, how does that work in settings that are structured?

Can it work in settings that are structured around labor and does trying to make it clear whose job it is and centralizing it, say in disability services, human resources, whatever, does that support that transition or not? Or how do we make it support that transition? Or for teachers, say, if you have a sense that this is somebody else's job, does that make you less likely to respond with

the sense of I'm ready and willing and able, and can see this as part of our relationship? Or hopefully it would make you more able to respond, which is, I know who can help me with that and who can help me solve this problem and make it not a problem and make it part of our relations of care. But to me, that's a real concern too, is how do you bring in that relationality and how can you do it in an institutional setting where you do need support and might have the possibility of support?

Jasmine Harris:

And frankly, I think of this in the context of higher education. That could be the perfect area, the perfect test ground for it, because many of us do this work anyway. We do the care work in how we interact with our students. And we value when they say that they're taking the weekend off, or they say that they're not going to get to our emails right away, or they need a break, they need a mental health day. At least in my class, I try to find ways to value those different measures of the person. And we have that flexibility as academics to do that. So, I think we are uniquely positioned to also say, as an institution, we're going to have, let's say, the administration value the care work that we do.

And this is the debate around diversity that we're hearing, where people of color in institutions, faculty of color are disproportionately bearing the burden of doing this work and things like diversity statements that go into tenure portfolios are an attempt to capture that care work that's happening right now. And so, I think, in terms of your point, Professor Emens, I'm really thinking about the higher education setting as one where we could come up with possible care metrics. There's a title for your paper, care metrics. And I think that would be worth thinking about.

So, I'm noticing that our queue is incredibly rich and robust. So, with your permission, with the permission of the both of you, I'm going to go straight to the queue and just have us keep talking, unless you have any additional comments on that last point. Okay, great. So, let's see. Here we go. So, this is a question for Professor Emens, but also, I think anyone can answer it. It says, "It's a really compelling set of presentations and ideas. This is a thought question for Professor Emens. I hear resonances in this project with the complaints of people of color about the unpaid and often unofficially recognize . . ." Okay, I didn't realize I was leaning into this question. "I wonder if situating your piece and dismantling structures of inequality of coursework, and that institutions need to value and support that work might help?" So, Katie Eyer and I are on the same page here. Unless you have additional remarks there, we could move on to the next question.

Elizabeth Emens:

I'll just say, absolutely. Thank you.

Jasmine Harris:

Okay. And then we have another question that says, "What would happen if we weren't so defensive about costs?" This is from Ruth Coker. "As Jasmine knows, my paper argues that the JAN data on accommodations likely understates the cost. Political conservatives claim to be pro-life, yet they obviously aren't. And of course, the cost are only so high because they are *post hoc* rather than *ex ante*, the ramp isn't installed. So, then it has to be a *post hoc* change."

And so, this is going to the point that I started with in saying that, should we just say that it is costly. Disability rights will cost. Civil rights are costly because of where we've started from, an ableist non-neurodiverse norm. So I'll open it up to both of you.

Kaaryn Gustafson:

They're costly, but they have benefits, right? In your discussion about the ADA as an effort to shift costs away from, I think Karen Tani mentioned this as well, a way . . . to shift costs out of the public benefits system so that people could participate in the workforce without discriminatory barriers. There are benefits to the system, they're just harder to assess. If we are only measuring the costs to employers, we tend not to be measuring the benefits to employers, the benefits to society, or the benefits to individuals with disabilities. And some of those costs aren't easily tallied. And it goes back to Jacobus tenBroeks' *The Right to Live in the World*.⁴⁰ The right to move about and participate in public life, which was much harder pre-ADA.

And some of those costs have been normalized. I mean, I'm old enough to remember life before the ADA, life before curb cuts. And my students can't even imagine that anywhere you would go in public, would be without curb cuts now. We have just normalized it. We have normalized accessible restrooms. We have come to expect ASL interpreters in public presentations. That's just a cost of allowing people to participate in society, but there are huge benefits. So that's the problem of the cost narrative, we ignore the benefits.

Jasmine Harris:

Professor Emens, do you want to comment?

⁴⁰ Jacobus tenBroek, *The Right to Live in the World: The Disabled and the Law of Torts*, 54 CALIF. L. REV. 841 (1966).

Elizabeth Emens:

I'll just add briefly. I really appreciate Professor Colker's question . . . And this is part of the question of infrastructure too, is if we're not willing to acknowledge that there are costs upfront, then institutions are less likely to be pushed to build infrastructure that will then create an apparatus of response and then each request is a cost. And so it may be that part of getting out of the cost frame in some sense, is being willing to fully confront the costs as opposed to trying to dodge them, and reframe them, and change them, and pretend they're not there. And so, I appreciate that intervention.

Jasmine Harris:

And just to also state the obvious, the cost to employers is offset by tax incentives, by particular grants, and so when we talk about the actual costs, we need to remember that you have to take the cost after all of these benefits are accounted for, which is actually the JAN argument that to do all of that, what's left is largely de minimus. I just wanted to jump in on what Professor Gustafson said. It made me think about COVID and it made me think about how we are beginning to talk about going back to "normal." And how it's not capturing the costs of individuals who are immunocompromised or who have family members who are immunocompromised and who have been isolated this entire pandemic. And so, it's not as if they were isolated and now they're going to come out or they'll be able to come out in a restricted phasing process.

They have been behind doors for two years, two plus years. And so, when we talk about the right to live in the world, that Jacobus tenBroek wrote about, I really think about the current situation with the pandemic. And I think, how do we capture those costs? Because the cost to the individuals of isolation, the costs of isolation for generations of children who are not together and being socialized and just quite frankly, getting into good and bad trouble developmentally. And so, these are the types of considerations that aren't currently captured by the cost-benefit analysis around covid. But I think it's salient to think what's happening away from the current conversation. Those people who cannot leave their homes and will not be able to leave their homes, because we want to go back to normal "too quickly," or we're done considering disability.

Kaayrn Gustafson:

Yeah. So I think there is a quiet subtextual discussion of cost going on. The founders talked about life, liberty, and property. And under the canons of construction, we would expect those to be in order of importance: life, liberty, and property. But we tend to give property prominence in analyses of

policy. I think what we're seeing in discussions about COVID is often cost to liberty—but not cost to liberty of those who are most vulnerable. We're hearing screaming mask debates about the costs of liberty to people who don't want to make any accommodations for people who might be vulnerable. So if we put life first, we would be pushing, probably, for stronger mask and vaccination mandates, but we're now at the liberty point in assessing costs and we are not looking at vulnerability in cost assessments. I think it's just a different cost narrative frame, but I think the cost narrative is still there.

Jasmine Harris:

Professor Emens, is there anything you want to add, or shall we go on to the next question? Okay.

So, most of these questions, again, I think although they're addressed to specific people, I think we can all opine on them. It says here, Professor Gustafson—this is from Nick Lawson—what makes you think death counts would be persuasive? Wouldn't many view higher death counts of people with disabilities as a good thing. They would just say that out loud. By the way, this is Jasmine speaking and I apologize for not doing this consistently.

And just to add one thing to the great question that Nick posed, Professor Gustafson, one of the things I was struck by was the fact that you said this would be really useful for practitioners, so practitioners could really implement this in terms of when thinking about cost and litigating their cases on the ground. And then I just thought, okay, so how would this work? We would need an expert because that's how courts understand anything related to disability, or anything scientific for that matter, in their mind. How would you deal with problems of causation or questions along those lines? How would we think that through? And I'd love to hear from practitioners as well and hope the practitioner panel tomorrow will pick up on it. But if you could please get us started with Nick's question and then my add on. Please, thank you.

Kaaryn Gustafson:

Yeah. So, going directly to Nick's question, I'm not convinced that death counts would be entirely persuasive. I think COVID has signaled that we become inured over time to death tallies, sadly. But if every piece of legislation also comes with a death count, I think it stands as a counter to dollar signs. And we can see there are other contexts where this comes in. So, there are studies showing, for example, that places where the minimum wage is lower have higher rates of suicide.⁴¹ That's a death count. Social scientists

⁴¹ Alex K. Gertner, Jason S. Rotter, & Paul R. Shafer, *Association Between State Minimum Wages and Suicide Rates in the US*, 56 Am. J. Preventative Med. 648 (2019); John Kaufman, Leslie K.

can do studies predicting the effects of minimum wage on suicide rates and use that to prompt lawmakers to raise the minimum wage. There were studies of states that did not take up adult dental coverage as part of their Medicaid programs, but there were higher death rates because poor dental health is linked to higher rates of infection and heart disease and other problems.⁴²

That's a way of using death counts on a practical level to say, yes, there are costs. Sometimes we may be saving costs [in public expenditures] but we are losing lives. And I think over time it just becomes a way of holding lawmakers accountable. I think it's a useful tool at a policy level. It's harder the closer down to the ground you get. And there is no clear and easy way of measuring [death] counts, but I also think that fights over estimates of premature deaths simply raise awareness that premature deaths will occur. If someone can say that a decision is death neutral, great. But if there is a positive death count by anyone's calculation—any social scientists' calculation, any economists' calculation—I think there is room to argue that it's problematic. And then, sorry, Jasmine, you had a second part?

Jasmine Harris:

I think you've actually answered most of it, which is it's not about the causation in a classic litigation sense, is what I hear you saying? And so, you wouldn't have someone get up on the stand necessarily and say this is a one-to-one relationship. Instead, you would talk about it in terms of the social determinants of health and other literature that's out there in policy analyses. Is that fair?

Kaaryn Gustafson:

Yeah.

Jasmine Harris:

Okay. Professor Emens.

Elizabeth Emens:

Yeah. So, this is Liz Emens. I just wanted to add, I've been thinking about, Professor Gustafson, since your really fascinating presentation, is trying to

Salas-Hernández, Kelli A. Komro & Melvin D. Livingston, *Effects of Increased Minimum Wages by Unemployment Rate on Suicide in the USA*, 74 J. EPIDEMIOLOG. COMMUNITY HEALTH 219, 220-21 (2020).

⁴² Brian P. Lee, Jennifer L. Dodge & Norah A. Terrault, *Medicaid Expansion and Variability in Mortality in the USA: A National, Observational Cohort Study*, 7 LANCET PUB. HEALTH. E48 (2022) (finding that Medicaid expansion is associated in all-cause mortality); Naveed Sadiq, Janice C. Probst, Amy B. Martin, M. Mahmud Khan & Anwar T. Merchant, *Untreated Dental Caries May be Associated with Subsequent Mortality among Working-Age Adults: Evidence from NHANES III*, 49 COMMUNITY DENT. ORAL EPIDEMIOLOG. 377 (2021).

see if I'm understanding in a way that this question helps me and your response to it, so I want to just ask if I'm getting it. In a sense, are you saying that a version of the cost frame matters? Pain, suffering matters. Some story of costs, which is likely to land and be salient for people, but you're trying to shift the metric from dollars to lives. And is one key element of that, the fact that then each life counts as one? That there is a way that if you have an overall count, then the hope would be that some lives are not discounted in that count, and at least the activists have that information and those who care have that information to work from in making arguments.

I guess my question then about it is the flip side, I suppose I wonder, is that aggregated data also matters to us, right? And being able to say, "Look who is disproportionately affected by this law." And once we've done that, do we lose some of the value of the everyone counts as one? And we're going to have one number, that maybe you could become salient, relative to, or even better than dollars in how people respond to, advertise, critique a law, or proposed law, or proposed rule of some kind. So, I don't know if you have a thought on that, but I'm just wondering both if I'm getting it, and if you have that concern as well about this possibility of shifting, at least, the cost frame.

Kaaryn Gustafson:

So, I do have thoughts on that, and I have two thoughts. One is, yes, treating all life as one is an equivalence argument, right. That every life is equally valuable, disabled, or non-disabled. And going back to Nick's question in the Q&A about maybe we want people who are disabled to die because they are expendable. I mean, I think those conversations have been out in the open during COVID, and even before. I mean, we can think about the debate several years ago. Ron Paul gave a talk on healthcare, arguing that we don't need . . . he was arguing against Obamacare and he was asked, well what happens if somebody isn't insured and somebody from the audience said, "Let them die."⁴³ And I think that, for many people in the US, has become part of the narrative around COVID. That it's [killing] *only* people who are elderly or *only* people who have disabilities. For a while it was, "Well, it's only people who are fat." And I heard this from doctors (who are dying at high rates from COVID), which is a dismissal of many, many people in the United States.

⁴³ This occurred during the CNN/Tea Party Express Republican Debate on September 12, 2011. For discussion of comments, which highlight public willingness to let the sick and uninsured die, see, Jacob Wiesberg, "*Let Him Die*": A Debate Question Exposes the Incoherence—and Cowardice—of the Republican Candidates' Opposition to Obamacare, SLATE (Sep. 13, 2011), <https://slate.com/news-and-politics/2011/09/let-him-die-a-debate-question-exposes-the-incoherence-and-cowardice-of-the-republican-candidates-opposition-to-obamacare.html>.

So yes, the tallies are treating every life as equal, but disaggregating the numbers is also a way of making equal protection arguments. It is saying “You all, you lawmakers passed this bill when there were tallies suggesting that there would be high rates of premature deaths among people with disabilities,” which might shift it to from ADA to equal protection (for high rates of premature deaths among African Americans or Native Americans). And so that looks like, not just knowledge, but intent that there will be disparities produced by the legislative decisions.

Jasmine Harris:

I do want to say that we received a comment from a superstar practitioner who does impact work and she very clearly said that this kind of death impact statement would be helpful. And so, I think and hope that maybe you can connect with some of the practitioners tomorrow and then moving forward, because I suspect that conversation back and forth about what would actually help in the advocacy and what might these statements look in terms of, as Professor Emens said, what are you capturing? By the way, this is Jasmine here speaking. Would you be capturing particular variables, et cetera. So, I wanted to first give you that information, so Professor Gustafson, you knew that it was resonating with practitioners, and second, encourage you to be in conversation with them as well.

Okay. And so, if I may move on to the next question. Let’s see, there’s a series of questions here. Here we go. “There’s a lot of discussion about ADA compliance costs on the internet in the long running circuit split regarding places of public accommodations. Does the ADA need to be updated for current technology? And if so, how? And what troubles do you foresee ahead if it is not, especially given the increased reliance on internet services since COVID.” If I may jump in and answer part of this question? The first thing I would like to say is that there is almost a knee jerk reaction that people have to amend the ADA when let’s say there’s a Democrat in office or a progressive. And so, there’s a lot of conversation that happens with academics and practitioners and they get asked, well, what reforms do you want to see for the ADA? Or if you have a Congress that seems friendly in terms of progressive movements, there’s that conversation happening and the political will to do so.

My response is that shared by, I think, several people who are participants here in this conference that that’s the wrong way to look at it. Disability is no longer a bipartisan issue. It may have been a bipartisan issue for perhaps the 1990s when it was largely white men who were advancing the cause of disability, it was something different. As people understand the intersectional nature of disability, disability has become closer to the treatment of other

historically marginalized identities. So, because of that, it's not a good time to open up the ADA to broader legislative reform, and I don't know that there is a good time to test the ADA in terms of accessibility, specifically with respect to websites. What we really need here is enforcement. And so, if you're going to ask me where should we put our time or effort? It should be in investing in agency regulations and agency guidance, specifically on accessibility. We got very close to getting some accessibility guidelines and guidance right before the end of the Obama administration. And then during the Trump administration, there was a hold on all agency action and rulemaking. If we go back to the drawing board and have actual regulations and then work on enforcement, and capacity, I think that's going to move the needle. So, I don't know if others have thoughts on that? Okay.

So, there's a question from, actually, I'm very excited to say, from two of my law students here. They're asking about reparations and how can we think about reparations in the context of disability. Who would owe such reparations? And the first thing to note is that California is now thinking through the reparations associated with compulsory sterilization and that history of forced sterilizations, and so I think that's probably in the background of the question.

Kaaryn Gustafson:

I mean, I think the reparations frameworks are always difficult, but sort of delicious to ponder. I think the most difficult . . . there are clear issues, especially with sterilization where you can identify the harms, but some of the harms with disability are so diffuse. The question is how do you measure them, right? That the widespread exclusion over time, I think it makes it much, much harder to quantify. But I really like the question and I'm going to spend a lot of time thinking about it.

Jasmine Harris:

Professor Emens, any thoughts? Okay. Let's move on. Thank you for the question. And let's move on to another set of questions from Professor Belt. I will try to summarize them, but basically Professor Belt is saying, are we really talking about "cripping" interest convergence here? Is that what we're talking about in terms of people who are non-disabled or in the mainstream will play ball, so to speak, and attend to issues of disability/accessibility when it benefits the whole. And so, are we kind of moving in that direction where

we're figuring out this cost benefit analysis? We're trying to frame it in a way that's the most persuasive way to do so.⁴⁴

Let me add on to that part with a second part of her question. I wish we could just unmute people because we have such great questions here. All right. I think we could start with that. But Professor Belt was trying to get to this point of how to think through the cost benefit analysis. How does this conversation relate to theories that come from critical race scholarship like Professor Derrick Bell's theory of interest convergence?⁴⁵ Anyone can answer that one.

Kaaryn Gustafson:

I'll say, yes, this is an effort to crip, at least mine is an effort to crip interest convergence, right? That along so many axes of vulnerability, disability is there. And few people are paying attention to it. And it lies at so many intersections that it just might be the way to create stronger coalitions.

Elizabeth Emens:

And I'll just add that I think we're always still stuck with the question of what enables people to see themselves as not yet disabled in ways that they're not currently disabled. Whether they're currently disabled or not, but especially people who haven't in any way claimed a disability identity, to invoke Katie Eyer's powerful work.⁴⁶ But if people haven't claimed a disability identity yet, then that leap into disability can sound in existential anxiety and in all those things that we talk about. And so, there are these structural and legal reforms. And yet if people aren't able to see themselves across this divide, I think it continues to be hard to figure out how that interest convergence works most powerfully where it should work. And to me, that's one of the big puzzles and it connects up of course to Professor Harris' work on the aesthetic dimension.⁴⁷

How do we bridge those divides? And so, the attitudinal piece, I think, has to come in here if what we're talking about is making effective use of interest convergence rather than the dark side of interest convergence. There are two stories. One is it only happens when it's a pandemic and non-disabled people or not yet disabled people are suddenly faced with this. Another version is there's a possibility of looking across and saying, "Oh wait, this

⁴⁴ Rabia Belt, ZOOM ("So I wonder if part of what Liz is talking about is "cripping" interest convergence — when powerful people want it, the investment is there, and it mutes the "this is costly" narrative?").

⁴⁵ Derrick A. Bell, Jr., Comment, *Brown v. Board of Education and the Interest-Convergence Dilemma*, 93 HARV. L. REV. 518 (1980).

⁴⁶ Katie Eyer, *Claiming Disability*, 101 B.U. L. REV. 547, 580-95 (2021).

⁴⁷ Jasmine E. Harris, *The Aesthetics of Disability*, 119 COLUM. L. REV. 895 (2019).

could be me.” And this is social insurance for everybody, and so we need to sign up and make this happen. How do we make that happen? How do we make that piece happen? And that’s where, I think, Professor Harris, your work (among other people’s) is so important in trying to solve those puzzles.

Jasmine Harris:

Thank you, Professor Emens. And I’m noticing that we are at time, but I did want to just add the last piece of Professor Belt’s question for us to be thinking about. And it’s also a question that I noticed earlier in the queue from Professor Rosemarie Garland-Thomson, and it’s this question of interest convergence or relationships with, for example, religious organizations.⁴⁸ So if we’re trying to move away from quantifying costs of life, in terms of money, then is there room for this kind of interest convergence and unlikely bedfellows with individuals who are pro-life? That’s a huge question. And so, in some ways it’s really unfair for me to end our round table with it, but I leave it here because we’re looking for alternative ways to think about costs, alternative ways to think affirmatively, what are the benefits that society gets, how do we change attitudes.

So, that’s going to come down to thinking creatively and sometimes thinking controversially about some of these issues that are cross-cutting, and disability has a ton of them. So, I do want to thank everyone for coming today. There are a host of questions we didn’t get to, but I encourage you to reach out or to read the work that is posted and the work that has been mentioned today and so much work that hasn’t been specifically referenced or posted.

Thank you, all. Thank you, Professor Emens, Professor Gustafson for such a wonderful, enriching discussion. I can’t wait to comment offline as well and talk to you about this great work that you’re doing. Thank you, everyone. This is Jasmine Harris, and, with that, I’m going to conclude our discussion.⁴⁹

⁴⁸ Rabia Belt, ZOOM (“Provocation here—is there a space for convergence with religious orgs to have a different way to value human life other than economic? Thinking of the Catholic Church during the heyday of eugenics.”) Unfortunately, Professor Garland-Thomson’s question was not preserved.

⁴⁹ The panel was not able to get to all questions in the queue due to time constraints. For additional thoughts on the cost frame, the unanswered questions may be found at https://www.dropbox.com/s/x4bomfepb4t2jz1/Day%201_Links%20to%20resources%20and%20unanswered%20questions.pdf?dl=0.